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Are life-extending treatments for terminal illnesses a special case? Exploring choices and societal viewpoints

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1   **Title:** Are life-extending treatments for terminal illnesses a special case? Exploring choices

2   and societal viewpoints

3

4   **Abstract**

5   Criteria used by the National Institute for Health and Care Excellence (NICE) to assess life-

6   extending, end-of-life (EoL) treatments imply that health gains from such treatments are

7   valued more than other health gains. Despite claims that the policy is supported by societal

8   values, evidence from preference elicitation studies is mixed and in-depth research has

9   shown there are different societal viewpoints. Few studies elicit preferences for policies

10   directly or combine different approaches to understand preferences.

11

12   Survey questions were designed to investigate support for NICE EoL guidance at national

13   and regional levels.   These 'Decision Rule' and 'Treatment Choice' questions were

14   administered to an online sample of 1,496 UK respondents in May 2014.   The same

15   respondents answered questions designed to elicit their agreement with three viewpoints

16   (previously identified and described) in relation to provision of EoL treatments for terminally

17   ill patients. We report the findings of these choice questions and examine how they relate

18   to each other and respondents' viewpoints.

19

20   The Decision Rule questions described three policies: DA – a standard 'value for money'

21   test, applied to all health technologies; DB – giving special consideration to all treatments

22   for terminal illnesses; and DC – giving special consideration to specific categories of

23   treatments for terminal illnesses e.g. life extension (as in NICE EoL guidance) or those that

1   improve quality-of-life (QoL). Three Treatment Choices were presented: TA – improving QoL

2   for patients with a non-terminal illness; TB – extending life for EoL patients; and TC –

3   improving QoL at the EoL.

4

5   DC received most support (45%) with most respondents giving special consideration to EoL

6   only when treatments improved QoL. The most commonly preferred treatment choices

7   were TA (51%) and TC (43%). Overall, this study challenges claims about public support for

8   NICE's EoL guidance and the focus on life extension at EoL and substantiates existing

9   evidence of plurality in societal values.

10

11

1 Introduction

In 2009 the National Institute of Health and Care Excellence (NICE) issued supplementary guidance for the appraisal of life-extending, end-of-life (EoL) treatments (NICE, 2009). This guidance permits such treatments to be recommended, even if they are not cost-effective according to usual standards, if certain criteria are met. These criteria are: 1) the treatment is for patients with short life expectancy normally less than 24 months, 2) the treatment would offer an extension to life of at least 3 months, and 3) the treatment is licensed for a small patient population (NICE, 2009). NICE, like other national Health Technology Assessment (HTA) organisations, has adopted an approach to economic evaluation based on cost utility analysis and applies a threshold cost per quality-adjusted life year (QALY) of £30,000 (NICE, 2013). For technologies that meet the EoL criteria a threshold of £50,000 per QALY has emerged over time (The Parliamentary Office of Science and Technology, 2015) implying that life-extending QALYs for patients with terminal illnesses are valued 1.7 times more than QALYs gained from all other types of treatment.

By raising the threshold for, or giving additional weight to, life-extending health gains at the EoL, the supplementary guidance suggests that these health benefits are of greater value (to society) than other types of health gains and that EoL might be considered a special case (Rawlins et al., 2010). However, empirical evidence of societal support for such a claim remains equivocal (Shah, 2017) and there is an opportunity cost to the EoL policy in terms of the health gains that would have arisen if spending had been allocated in other ways (Collins and Latimer, 2013). In this study, we examine societal preferences for provision of life-extending treatments for people with a terminal illness using two types of survey question, presenting respondents with choices between 'Decision Rules' (designed to reflect policies

1   of the type that might be applied by national HTA organisations) and 'Treatment Choices' (of

2   the kind that might be made by a regional health board with a fixed budget).

3

4   **Background**

5   Empirical studies that elicit societal values around EoL have deployed a variety of methods,

6   including discrete choice methods (DCM) (Rowen et al., 2016; Shah et al., 2015a; Skedgel et

7   al., 2015), person trade-off (PTO) (Pinto-Prades et al., 2014), budget allocation (Linley and

8   Hughes, 2013) and willingness to pay (WTP) (Pennington et al., 2015; Pinto-Prades et al.,

9   2014). The results of these studies have been remarkably mixed. In a recent literature

10 review, Shah (2017) identifies 20 papers reporting empirical studies of societal values and

11 EoL. Seven papers find a positive premium for EoL, nine negative and four report mixed

12 findings (see Shah (2017) for a detailed summary of these papers). Of these studies only

13 three examined preferences for different types of health benefit at the EoL; Pinto-Prades et

14 al. (2014) and Shah et al. (2014) found a preference for quality-of-life improvements and

15 Shah et al. (2015b) a preference for life extensions. The reason for such mixed findings is not

16 clear (Shah, 2017) but it is difficult to explain wholly on the basis of study design, sampling

17 or elicitation methods.

18

19 One possible explanation is that such mixed findings reflect substantial moral disagreement.

20 This hypothesis is supported by the findings of the first phase of a two-phase study (funded

21 by the Medical Research Council (MRC) Methodology Panel: project ID number G1002324)

22 that used Q methodology to understand the nature of UK societal perspectives around the

23 relative value of life extensions for people with a terminal illness (McHugh et al., 2015). Q

1   methodology combines qualitative and quantitative methods to study 'subjectivity' –

2   opinions, beliefs or values (Stephenson, 1953; Watts and Stenner, 2012). Data collection is

3   via a card sort, and by-person factor analysis enables shared views around a given topic to

4   be identified and then described; this methodology has previously been applied to the field

5   of health (Baker et al., 2006; van Exel et al., 2015). Using this methodology we identified

6   three viewpoints: i) 'A population perspective – value for money, no special cases', ii) 'Life is

7   precious – valuing life-extension and patient choice', iii) 'Valuing wider benefits and

8   opportunity cost – the quality of life and death'. These viewpoints (described in detail in the

9   original paper) highlight the plurality of views that exist in society around this topic and

10   indicate that current NICE EoL policy may find little support. The viewpoints in this first

11   phase of work are based around statements of opinion, principles and values relating to the

12   provision of life-extending treatments at the EoL. As such, they are more abstract than

13   most preference elicitation tasks, which tend to describe specific (albeit hypothetical)

14   choices and trade-offs. A clear strength of preference elicitation studies is that opportunity

15   cost is presented in terms of the choice foregone or through WTP (both imply budget

16   constraints). However, preference elicitation scenarios are often attribute-based, can be

17   brief or unrealistic and support for policy tends to be inferred by aggregating responses to

18   these tasks. In the context of EoL, preference elicitation studies have resulted in such mixed

19   findings that simple aggregation and measures of central tendency likely conceal

20   heterogeneity. Combining preference elicitation with other approaches might shed light on

21   both the mixed findings in the existing literature and whether respondents are consistent

22   between their viewpoints and stated preferences.

23

On the rare occasions that different approaches have been combined to examine societal values and EoL, inconsistent results have been found. Rowen et al. (2014) presented attitudinal questions to respondents, following a series of choice-based questions designed as a Discrete Choice Experiment (DCE). Despite their DCE results indicating some support for an EoL premium, responses to attitudinal questions suggested limited support for life-extending treatments and patients at the EoL. Shah et al. (2015b) explored whether respondents agreed with the policy implications of their responses to stated preference tasks. Respondents were first asked to make choices between pairs of scenarios that were either abstract or 'real-world' resource allocation decisions (the latter included qualitative descriptions of patients' quality-of-life and information about the ages of patients instead of conceptual diagrams depicting information about patients, medical conditions and treatments as used in the former), and then were asked to state their agreement (or not) with the implied policy implication of their choice. Results suggested that some respondents struggled to align their views with the need to make specific trade-offs around prioritisation decisions and that disagreement with the policy implications of their choice could result from respondents differing interpretation of policies. These results imply that responses to specific choices and trade-offs may not align with more general beliefs or views around life-extending EoL treatments and that further exploration of this could help us understand the mixed, empirical EoL findings.

In this paper we examine responses to specific choices as well as agreement with more abstract viewpoints in relation to the provision of life-extending treatments for people with a terminal illness ('terminal illness' and 'EoL' are used interchangeably as the NICE supplementary guidance uses the term 'EoL' (NICE, 2009) and their definition implies

1 'terminal illness'). Respondents were asked to make choices framed with respect to policies

2 at a national level ('Decision Rule') and treatment provision at a regional level ('Treatment

3 Choice'). One scenario in each case is designed to mirror NICE EoL guidance. We elicit

4 respondents' support for the societal viewpoints identified in our earlier Q methodological

5 work (McHugh et al., 2015). We then examine how choices between Decision Rules and

6 Treatment Choices correspond to each other and to the wider societal viewpoints.

Methods

7

Survey Design

8

9 The survey was split into different versions, one of which incorporated the Decision Rule

10 and Treatment Choice questions. In addition to these policy choice questions (described in

11 more detail below) respondents were asked to give Likert scale responses (Viewpoint

12 Questions) to indicate (dis)agreement with the three viewpoints identified in McHugh et al.

13 (2015). The questionnaire concluded with socio-demographic questions. Appendix 1 shows

14 the script used in the introductory animation and Appendices 2-4 detail the text of each

15 question (accessed online at: http://www.gcu.ac.uk/endoflife/onlinesurvey/).

16

Decision Rule Design

17

18 The Decision Rule (D) question (see Appendix 2) was designed to represent the types of

19 high-level rules applied to coverage decisions, at a national level, by bodies like NICE and the

20 Scottish Medicines Consortium (SMC) in the UK. Specifically, respondents were asked to

21 select how a health system should assess drugs for terminally ill patients that would not

22 pass a standard 'value for money' (VFM) test (used as a lay term for cost effectiveness – see

1 'Notes' in Appendix 2 for definition). Respondents were then presented with a choice

2 between three mutually exclusive policies: DA – a standard VFM test applied to all new

3 health technologies ('DA – standard VFM test'); DB – permitting 'special consideration' (i.e.

4 provision of treatments even if the VFM is not passed) for all EoL treatments ('DB – special

5 consideration EoL'); and DC, permitting special consideration to specific categories of new

6 treatments for terminal illnesses, such as those that extend life only or improve QoL only

7 ('DC – EoL ….. it depends'). DC is most like the NICE EoL supplementary guidance for those

8 respondents selecting life extension as the specific reason for special consideration.

9

10 **Treatment Choice Design**

11 The Treatment Choice question (see Appendix 3) was designed to represent the types of

12 decision that might be faced by Health Boards or Clinical Commissioning Groups, confronted

13 with a fixed, additional budget. Respondents first selected their most-preferred treatment

14 (A-C) then their second-best treatment and following this one reason (from a closed set of

15 options) for their choice of most-preferred treatment. Next, respondents were presented

16 with two PTO questions (pairing their most-preferred versus second-best treatments and

17 their most-preferred versus least-preferred treatments). TA – improving quality-of-life for

18 100 patients with a non-terminal illness (TA – Non-EoL-QoL) episodically for the rest of their

19 life; TB - extending life by three months for 100 EoL patients (TB – EoL-LE), and TC -

20 improving symptoms for 100 patients in the last year of their life (TC – EoL-QoL). The size of

21 the health gain from TA, TB and TC was implied rather than explicitly stated within the

22 treatment descriptions.

23

1   The PTO questions required respondents to choose between providing treatment to one of

2   two patient groups in the context of a fixed budget (only one patient group could be

3   treated); the number of patients in each group was initially set as equal (100). Respondents

4   were then asked to imagine that the cost of their preferred treatment changed, meaning

5   fewer patients could be treated in their preferred group, while the other treatment could

6   still treat 100 patients. The number of patients in their preferred treatment group was

7   altered between low and high numbers of treated patients, until a point of indifference was

8   reached (Nord, 1995).

9

10   **Viewpoint Questions Design**

11   The Viewpoint Questions were designed to measure respondents' agreement with one of

12   three viewpoints, identified in earlier, in-depth research using Q methodology. The first

13   viewpoint – *'A population perspective – value for money, no special cases'* – is a broadly

14   utilitarian, system-level perspective. Importance is given to maximizing the health benefits,

15   from a fixed health budget, to a population. Accordingly treatments that yield greatest

16   health improvements in relation to cost should be prioritized and all patient groups should

17   be considered equally deserving of treatment. The second viewpoint – *'Life is precious –*

18   *valuing life-extension and patient choice'* – is an individual patient perspective and is based

19   on rights-based arguments and views about entitlement. Human life is considered precious

20   and treatments should not be denied because of cost. Consequently no treatments are

21   viewed as being a special case, rather the key criteria is that if a patient wants a treatment,

22   including life-extending treatments at the EoL, they should have it because everyone

23   contributes to the funding of the NHS. The third viewpoint – *'Valuing wider benefits and*

24   *opportunity cost - the quality of life and death'* – is similar to the first as it recognizes the

importance of achieving value for money from the health budget. However, this viewpoint also appreciates that there may be value for patients and their families from receiving treatment that goes beyond the measurable health benefits typically used in standard cost-benefit calculations. For more detail on these viewpoints see McHugh et al. (2015).

Salient and distinguishing statements from the original Q study were selected to characterise each of the viewpoints (see Appendix 4) following methods described in Baker et al. (2010a), Baker et al. (2014) and Mason et al. (2016). Six statements were identified to distinguish each of the three viewpoints, resulting in a set of 18 statements selected from the original 49 statements (McHugh et al., 2015). Crucially, these statements are used as 'flags' to signal allegiance with the whole viewpoint, they do not 'sum up' the viewpoint in its entirety.

Each of the 18 statements was presented to survey respondents, in random order, accompanied by a 7-point Likert scale labelled from "completely disagree" to "completely agree". On completion, three scores were calculated for each respondent, indicating their level of agreement with each of the three viewpoints. Respondents were assigned to the viewpoint consistent with their highest score and to the category 'mixed' if their highest scores were equal on more than one viewpoint.

Data Collection

The online survey was programmed and administered by YouGov (www.yougov.co.uk) and

can be viewed and completed via the project website:

http://www.gcu.ac.uk/endoflife/onlinesurvey/.

Prior to programming, survey questions were piloted in six focus groups with members of

the public (n=54), recruited via a market research company to ensure variation across socio-

demographic characteristics (age, gender and income). In addition, prior to and after

programming survey questions were piloted with a convenience sample of university

colleagues to test the design, wording and comprehension of questions. Qualitative probing

during the pilot led to a better understanding of how respondents interpreted the questions

and question wording was amended accordingly. For example, in TA (Non-EoL-QoL)

respondents asked if the duration of quality-of-life improvement was for the rest of the

patients' life so the words "for the rest of their life" were added.

Respondents to the main survey were quota sampled from YouGov's UK online survey panel

to represent the UK population on the basis of age, gender, socio-economic group (SEG) and

ethnicity.

The survey was structured as follows: first, a short animated video (created specifically for

this project) introduced and set the context for the survey (see

http://www.gcu.ac.uk/endoflife/onlinesurvey/introductoryanimation/).   The   video

describes, in simple terms, the issues of scarcity and opportunity cost within the NHS and

the need to make decisions about the provision of treatments and services. It explains that

1 many different things could be considered when making decisions about how best to

2 allocate resources, such as severity of illness or quality-of-life, and that in this research the

3 focus was on treatments that help terminally ill patients live longer (see Appendix 1).

4

5 Following the introduction, the 18 Viewpoint Questions were presented followed by the

6 Decision Rule and then Treatment Choice questions. The survey finished with a number of

7 socio-demographic questions.

8

Data Analysis

10 As online surveys are susceptible to 'clicking through' and to respondents being distracted,

11 those who completed the survey very quickly (less than 7 minutes and 30 seconds) or very

12 slowly (longer than 2 hours) were excluded from the analysis. Respondents who completed

13 the survey in less than 7 minutes and 30 seconds, were considered to have reached

14 completion too quickly to have fully read and understood the tasks. Similarly, those

15 respondents who took more than 2 hours to reach completion, might not have fully

16 engaged with the survey and the time taken to complete may have inhibited their ability to

17 recall the premise of the survey outlined in the introductory video. It is possible that, by

18 imposing these rules, valid responses were excluded. However, these conservative cut-off

19 times were based on the judgment of the research team informed by timed testing of the

20 survey. Sensitivity analysis was conducted to examine the impact of imposing these

21 exclusions on findings.

22

1   Summary statistics detailing frequencies for both the Decision Rule and Treatment Choice

2   questions were calculated. Hypotheses about which choice of treatment would logically

3   follow from respondents' decision rule are shown in Table 1.

4

5   **Table 1 Hypotheses: Decision Rule and Treatment Choice**

Decision Rule	Treatment Choice		
	TA (Non-EOL-QoL)	TB (EoL-LE)	TC (EoL-QoL)
DA (standard VFM test)	Yes	No	No
DB (special consideration EoL)	No	either potentially consistent	
DC (EoL ….. it depends)	No	either potentially consistent	

6

7   If respondents' choice of treatment reflects their decision rule those selecting Decision Rule

8   DA would be more likely to choose Treatment Choice TA as this choice reflects a preference

9   for maximizing health gains from a fixed budget. Respondents selecting DB favour all

10   treatments for terminal illnesses so are likely to choose TB or TC. Similarly these two

11   treatments – TB and TC – are also likely to be selected by those who prefer DC.

12

13   PTO ratios were calculated, reflecting respondents' strength of preference for treatment

14   choices. While there is no single, correct approach for aggregating PTO ratios, there is

15   consensus that one method – calculating the 'mean of ratios' – should be avoided. Following

16   Baker et al. (2010b), Chilton et al. (2002), and Pinto-Prades et al. (2014), we calculated the

17   'ratio of means' and the 'median of ratios' (see Appendix 5 for details and illustrative

18   calculations).

19

20   The relationship between respondents' decision rule and treatment choices and their

21   viewpoints was also hypothesised (see Table 2). Similar predictions (as detailed in Table 1)

1. were made about which choices of decision rule and treatment choices would logically

2. follow from respondents' viewpoints.

3.

4. **Table 2 Hypotheses: Viewpoints and Policy Choices**

Views	Decision Rule				Treatment Choice		
	DA (standard VFM test)	DB (special consideration EoL)	DC (EoL ….. it depends)		TA (Non-EoL-QoL)	TB (EoL-LE)	TC (EoL-QoL)
Viewpoint 1 (A population perspective: value for money, no special cases)	Yes	No			Yes	No	
Viewpoint 2 (Life is precious: valuing life-extension and patient choice)	No	Unclear			Unclear		
Viewpoint 3 (Valuing wider benefits and opportunity cost: the quality of life and death)	Unclear	No	Yes		Yes	No	Yes

5.
6. If choices reflect viewpoints then respondents associated with Viewpoint 1 (a broadly

7. utilitarian account) would be more likely to choose Decision Rule DA and Treatment Choice

8. TA because these choices would maximize health benefits. Respondents associated with

9. Viewpoint 2 believe that patient choice is paramount and life is precious, and that cost

10. should not drive decisions about treatment provision so no clear decision rule or treatment

11. choice preference follow. We might predict, however, that those holding Viewpoint 2

12. would object to a strict value for money approach that overrules patient choice on the

13. grounds that they reject consideration of cost. Respondents who agree most with

14. Viewpoint 3 are likely to prefer DC, TA and TC as quality-of-life is reflected in these choices;

15. DA could also be chosen because of value for money concerns but may be considered too

16. narrow a decision rule for this account.

17.

1 **Research Ethics**

2 Ethical approval for this study was obtained from the School of Health and Life Sciences

3 Ethics Committee, Glasgow Caledonian University (reference B11/04).

4

5 **Results**

6 **Sample size, exclusion criteria and characteristics**

7 Data were collected in May 2014. The full sample across all survey versions totaled 5,496

8 respondents and was quota sampled from YouGov's online panel to be nationally

9 representative with respect to age, gender, SEG and ethnicity. 1,657 respondents were

10 randomly allocated to the Policy Choice Version; after exclusion of respondents based on

11 completion times the Policy Choice Version totaled 1,496 (Table 3 details respondents socio-

12 demographic characteristics in total and according to their policy choices). Sensitivity

13 analysis showed that the use of exclusion rules made no difference to the percentages

14 selecting options within the Decision Rule and Treatment Choice questions.

15

16 **Relationship between policy choices and respondent characteristics**

17 The relationship between respondents' socio-demographic characteristics and their policy

18 choices (Decision Rule and Treatment Choice) is shown in Table 3. Respondents' gender,

19 age, ethnicity, SEG, education and income were statistically significantly related to their

20 choice of Decision Rule. Males were more likely to choose DA and females to choose DC;

21 those selecting DB were younger than those selecting DA or DC and more-likely to be non-

22 white; those with high educational qualifications, socio-economic status and income more

1 often selected DA whereas respondents with low qualifications and income more often

2 chose DB. Responses to Treatment Choice questions appeared to be related to gender, age,

3 and education but in general, there were fewer statistically significant relationships. Males

4 were more likely to choose TB and females to choose TC; those selecting TB were younger

5 than those selecting TA or TC; and those with low educational qualifications chose TB

6 whereas those with high qualifications selected TA.

7

8 **Table 3: Respondent characteristics: Total sample, Decision Rule and Treatment Choice**

Variables	Total Sample		Decision Rule							P^	Treatment Choice						P^
			DA (standard VFM test)		DB (special consideration EoL)		DC (EoL ….. it depends)				TA (Non-EoL-QoL)		TB (EoL-LE)		TC (EoL-QoL)		
	N	%	N	%	N	%	N	%			N	%	N	%	N	%	
Gender										0.1[a]*							<0.01[a]***
Male	**739**	**49.4**	282	52.8	145	49.5	312	46.6			386	50.6	54	63.5	299	46.1	
Female	**757**	**50.6**	252	47.2	148	50.5	357	53.4			377	49.4	31	36.5	349	53.9	
Age										0.03[a]**							<0.01[a]***
18-29	**247**	**16.5**	91	17	61	20.8	95	14.2			133	17.4	18	21.2	96	14.8	
30-49	**511**	**34.2**	165	30.9	105	35.8	241	36.0			256	33.6	42	49.4	213	32.9	
50-64	**380**	**25.4**	133	24.9	74	25.3	173	25.9			184	24.1	20	23.5	176	27.2	
65-74	**197**	**13.2**	78	14.6	29	9.9	90	13.5			97	12.7	4	4.7	96	14.8	
75+	**161**	**10.8**	67	12.5	24	8.2	70	10.5			93	12.2	1	1.2	67	10.3	
Ethnicity										0.02[a]**							0.4[a]
White	**1,364**	**91.2**	497	93.1	254	86.7	613	91.6			701	91.9	74	87.1	589	90.9	
Non-white	**104**	**7**	30	5.6	31	10.6	43	6.4			50	6.6	9	10.6	45	6.9	
Prefer not to say	**28**	**1.9**	7	1.3	8	2.7	13	1.9			12	1.6	2	2.4	14	2.2	
Country										0.9[b]							0.3[b]
England	**1,227**	**82**	439	82.2	239	81.6	549	82.1			627	82.2	73	85.9	527	81.3	
Wales	**80**	**5.3**	28	5.2	16	5.5	36	5.4			32	4.2	5	5.9	43	6.6	
Scotland	**165**	**11**	61	11.4	31	10.6	73	10.9			91	11.9	7	8.2	67	10.3	
Northern Ireland	**24**	**1.6**	6	1.1	7	2.4	11	1.6			13	1.7	0	0	11	1.7	
SEG[c]										0.02[a]**							0.8[a]
AB (SEG)	**461**	**31**	178	33.5	75	25.7	208	31.4			234	30.9	22	25.9	205	31.8	
C1 (SEG)	**451**	**30.3**	167	31.4	93	31.8	191	28.8			230	30.4	29	34.1	192	29.8	
C2 (SEG)	**234**	**15.7**	86	16.2	49	16.8	99	14.9			125	16.5	14	16.5	95	14.7	
DE (SEG)	**341**	**22.9**	101	19	75	25.7	165	24.9			168	22.2	20	23.5	153	23.7	
Education Qualifications										<0.01[a]***							0.06[a]*
Low qualifications	**350**	**23.4**	108	20.2	86	29.4	156	23.3			166	21.8	27	31.8	157	24.2	

Variables	Total Sample		Decision Rule								Treatment Choice							
			DA (standard VFM test)		DB (special consideration EoL)		DC (EoL ….. it depends)		P^		TA (Non-EoL-QoL)		TB (EoL-LE)		TC (EoL-QoL)		P^
	N	%	N	%	N	%	N	%			N	%	N	%	N	%	
Mid qualifications	**398**	**26.6**	132	24.7	77	26.3	189	28.3			198	26.0	20	23.5	180	27.8	
High qualifications	**712**	**47.6**	283	53.0	122	41.6	307	45.9			383	50.2	35	41.2	294	45.4	
Don't know	**9**	**0.6**	1	0.2	3	1.0	5	0.7			5	0.7	1	1.2	3	0.5	
Prefer not to say	**27**	**1.8**	10	1.9	5	1.7	12	1.8			11	1.4	2	2.4	14	2.2	
Income									<0.01 [a]***								0.8 [a]
Low income	**349**	**23.3**	106	19.9	82	28.0	161	24.1			180	23.6	19	22.4	150	23.1	
Middle income	**444**	**29.7**	163	30.5	80	27.3	201	30.0			237	31.1	25	29.4	182	28.1	
High income	**341**	**22.8**	148	27.7	57	19.5	136	20.3			178	23.3	15	17.6	148	22.8	
Don't know	**80**	**5.3**	26	4.9	18	6.1	36	5.4			36	4.7	4	4.7	40	6.2	
Prefer not to answer	**282**	**18.9**	91	17.0	56	19.1	135	20.2			132	17.3	22	25.9	128	19.8	
Total	**1,496**		**534**	**35.7**	**293**	**19.6**	**669**	**44.7**			**763**	**51**	**85**	**5.7**	**648**	**43.3**	

1 ^ 'Don't know' & 'Prefer not to say' excluded from p-value calculation.
2 [a] Kruskal-Wallis tests. [b] Chi-Square tests. [c] n=1487 because of missing data. ***1% significance level; **5%
3 significance level; *10% significance level.
4

1   **Decision Rule Results**

2   Table 4 shows the results from the Decision Rule question. DB was the least popular policy

3   when respondents were asked 'which one of the following policies do you agree with

4   most?', and overall there was a preference for giving special consideration to treatments for

5   terminal illnesses in some (albeit not all) situations. Of the 669 respondents who selected

6   DC, a large majority (72%) stated that treatments that improve quality-of-life for terminally

7   ill patients should be given special consideration; only 10% stated special consideration

8   should be given to treatments that extend life. When asked about the role cost should play

9   in the provision of DB or DC, 56% of the 293 respondents who preferred DB thought this

10   policy should be implemented regardless of cost, whereas 63% of the 669 respondents who

11   preferred DC agreed there should be some limit to the amount the NHS pays to implement

12   this policy.

13

14   **Table 4 Decision Rule Results and Reasons (n=1,496)**

	DA (standard VFM test)	DB (special consideration EoL)	DC (EoL ….. it depends)	
Total selecting this policy	534 (36%)	293 (19%)	669 (45%)	
Valuing types of health gain			Improve QoL	485 (72%)
			Extend Life	64 (10%)
			Depending on . .*	120 (18%)
Regardless of cost		165 (56%)	246 (37%)	
Limit to cost		128 (44%)	423 (63%)	

26   *Special consideration depends on something else, either: patients having known about their terminal illness
27   for only a short period of time; patients not having had their fair innings in terms of length of life; life extension
28   only being valued if quality-of-life is not poor or another (entered) reason.
29

1 **Treatment Choice Results**

2 **Ranking Results and Reason for Choice**

3 Table 5 presents the ranking results from the Treatment Choice question. Just over half of

4 respondents (51%) chose to provide TA from the additional available budget (quality-of-life-

5 improving treatment for non-terminal illness (Non-EoL-QoL)). A substantial number of

6 respondents (43%) preferred TC (quality-of-life-improving treatment for a terminal illness

7 (EoL-QoL)); only 6% preferred TB (life-extending treatment for a terminal illness (EoL-LE)).

8 Examination of second-choice treatments reveals that TB (EoL-LE) remains the least-

9 preferred treatment, while more respondents prefer TC (EoL-QoL) (48%) to TA (Non-EoL-

10 QoL) (35%). The majority of respondents placed TB in third place (78%), whereas TC was

11 ranked third by the least number of respondents (9%).

12

13 **Table 5 Treatment Choice Ranking Results**

		Total (%)	Second choice (%)		
			TA (Non-EoL-QoL)	TB (EoL-LE)	TC (EoL-QoL)
First choice (%)	**TA (Non-EoL-QoL)**	**763 (51.0)**		93 (6.2)	670 (44.8)
	TB (EoL-LE)	**85 (5.6)**	38 (2.5)		47 (3.1)
	TC (EoL-QoL)	**648 (43.4)**	489 (32.7)	159 (10.6)	
Total (%)		**1,496 (100)**	**527 (35.2)**	**252 (16.8)**	**717 (47.9)**

14

15 Respondents also chose one reason for selecting their preferred choice of treatment.

16 Respondents who most-preferred TA did so because it would provide a larger health benefit

17 gain (34%), it would improve quality-of-life (26%) and the illness affects patients for the rest

18 of their life (22%). Quality-of-life improvement was also the primary reason behind the

19 preferred selection of TC (77%). Those preferring TB did so mainly because it would extend

20 life (50%).

1

PTO Results

3 PTO questions paired respondents' most-preferred versus second-best treatment (1 vs. 2)

4 and most-preferred versus least-preferred treatment (1 vs. 3); the totals in Table 5 detail

5 the aggregated order in which each of the three treatments was ranked. Data from both

6 PTO questions – 1 vs. 2 and 1 vs. 3 – were combined in order to aggregate responses for

7 each pair of treatments – TA and TB, TA and TC and TB and TC. Counts, ratios and 'extreme

8 preferences' (taken as the number of respondents who consider that fewer than 10 patients

9 receiving one treatment is equivalent to 100 patients receiving the other) are shown in

10 Table 6.

11

12 **Table 6 Treatment Choice PTO results**

X vs. Y	TA (Non-EoL-QoL) vs. TB (EoL-LE)	TA (Non-EoL-QoL) vs. TC (EoL-QoL)	TC (EoL-QoL) vs. TB (EoL-LE)
Prefer X (%)	763 (90%)	763 (54%)	648 (88%)
Extreme preference: <10X = 100Y	450 (59%)	335 (44%)	388 (60%)
Prefer Y (%)	85 (10%)	648 (46%)	85 (12%)
Extreme preference: <10Y = 100X	37 (44%)	330 (51%)	35 (42%)
Mean prefer X	33	65	35
Mean prefer Y	95	70	94
Ratio of means X:Y (Y=1)	0.34	0.93	0.37
Median of ratios (Y=1)	0.08	0.98	0.08
Total	**848**	**1411**	**732***

13 *PTO 1 v 3 data is missing from one individual.

14

15 While the initial ranking of treatments (see Table 5) indicates the ordering of treatments,

16 examination of PTO data provides insight into the magnitude of preferences between pairs

17 of treatments. For the pair TA versus TC both (the 'ratio of means' and the 'median of

ratios') are close to one, suggesting that respondents value the two treatments similarly (0.93 and 0.98). Ratios indicate greater strength of preference for TA or TC when compared to TB.

In an attempt to 'unpack' the data a little, Table 6 also shows 'extreme preferences'. While a substantial proportion of respondents' make these extreme choices, the most pronounced differences are seen in the pairings when either TA or TC is set against TB (59% v 44% and 60% v 42%). In pair TA versus TC, despite ratios suggesting a slight preference for TA over TC there is a greater proportion of extreme preferences among respondents who prefer TC than those who prefer TA (51% vs. 44%). This is balanced against the fact that a greater number of respondents prefer TA.

The results of Treatment Choice, like the Decision Rule questions, indicate a preference for quality-of-life improving treatments for both non-terminal and terminal illnesses compared to life-extending treatments for the terminally ill.

Relationship between Decision Rule and Treatment Choices

Table 7 cross-tabulates Decision Rule and Treatment Choices. As hypothesised (see Table 1), those who selected DA more often chose TA (70%) and to a lesser extent TC (27%); TB was rarely chosen. Those who selected DB most commonly chose TC (57%), as predicted, but, unexpectedly, more DB respondents selected TA (33%) than chose TB (10%). This pattern of response was the same for DC respondents: most chose TC (50%) as expected but a large number selected TA (44%) over TB (6%). This latter result is not wholly surprising,

1 though, given that the majority of respondents who chose DC stated special consideration

2 depends on improvements in quality-of-life (see Table 4).

3

4 **Table 7 Relationship: Decision Rule and Treatment Choice**

		Treatment Choice			Total
		TA (Non-EoL-QoL)	TB (EoL-LE)	TC (EoL-QoL)	
Decision Rule	**DA (standard VFM test)**	70.0%	2.8%	27.2%	**534**
	DB (special consideration EoL)	33.1%	10.2%	56.7%	**293**
	DC (EoL ….. it depends)	43.6%	6.0%	50.4%	**669**
Total					**1,496**

5

Relationship between Viewpoints and Policies

7 The results in Table 8 show that 37% of respondents were matched with Viewpoint 1 ('A

8 population perspective – value for money, no special cases'). Just under half of the

9 respondents (49%) were matched with Viewpoint 2 ('Life is precious – valuing life-extension

10 and patient choice') and 9% matched with Viewpoint 3 ('Valuing wider benefits and

11 opportunity cost – the quality of life and death').

12

13 Table 8 shows a statistically significant pattern between respondents' viewpoints and their

14 policy choices; this pattern broadly reflects the hypotheses outlined in Table 2. Respondents

15 associated with Viewpoint 1 were more likely to choose Decision Rule DA (56%) than DC

16 (36%) or DB (8%) and, also as predicted, favour Treatment Choice TA (69%). Predictions

17 were more difficult for Viewpoint 2 for reasons already mentioned. However, as expected,

18 DA, which proposes a strict value for money approach, was the least preferred decision rule

19 for those associated with Viewpoint 2 (17%). Unexpectedly respondents who were

20 associated with Viewpoint 3 were more likely to select DA (53%) then DC (36%); few chose

21 DB (11%). As predicted Viewpoint 3 respondents were more likely to choose a quality-of-life

1	improving treatment – TA (62.4%) or TC (36%) – than one that extends life TB (2%).

2	Respondents associated with Viewpoint 1 and Viewpoint 3 had a similar pattern of response

3	to Decision Rule and Treatment Choice questions which could be a result of the relatively

4	high correlation (0.68) between these viewpoints (McHugh et al., 2015). Although this may

5	also relate to the relatively small number of respondents identified as Viewpoint 3 (n=141).

6

7	**Table 8 Respondent Viewpoints and Policy Choices**

Variables	Total Sample	Decision Rule				Treatment Choice			
		DA (standard VFM test)	DB (special consideration EoL)	DC (EoL ….. it depends)	P^	TA (Non-EoL-QoL)	TB (EoL-LE)	TC (EoL-QoL)	P^
	N	N (%)	N (%)	N (%)		N (%)	N (%)	N (%)	
Viewpoint					<0.01***				<0.01***
V1: A population perspective: value for money, no special cases	**558**	311 (55.7)	47 (8.4)	200 (35.9)		385 (69.0)	13 (2.3)	160 (28.7)	
V2: Life is precious: valuing life-extension and patient choice	**736**	128 (17.4)	218 (29.6)	390 (53.0)		258 (35.0)	66 (9)	412 (56.0)	
V3: Valuing wider benefits and opportunity cost: the quality of life and death	**141**	74 (52.5)	16 (11.3)	51 (36.2)		88 (62.4)	3 (2.1)	50 (35.5)	
Mixed	**61**	21 (34.4)	12 (19.7)	28 (45.9)		32 (52.5)	3 (4.9)	26 (42.6)	
Total	**1,496**	**534 (35.7)**	**293 (19.6)**	**669 (44.7)**		**763 (51.0)**	**85 (5.7)**	**648 (43.3)**	

8	^ p-values calculated using Chi-Square tests (the 'mixed' category was excluded from the calculation). ***1%
9	significance level.

Discussion

11	This paper reports the findings of a national survey of the UK general population

12	investigating societal preferences for provision of life-extending treatments for people with

13	a terminal illness framed with respect to policies at a national level (Decision Rule) and

14	treatment provision at a regional level (Treatment Choice). Results challenge NICE's current

15	EoL guidance as there is very little support for prioritising life-extending treatments for

16	terminal illnesses over and above other treatments. Substantial support is found for quality-

1   of-life improving treatments at the EoL and for policies which account for the costs of new

2   treatments.

3

4   While Decision Rule findings showed the majority of respondents supported giving special

5   consideration to assessing treatments for terminal illnesses (taking DC and DB together),

6   this finding was qualified. More support was given to DC, which suggests that special

7   consideration should be given to terminal illnesses in health care priority setting only in

8   certain situations; with a focus on treatments that improve quality-of-life. Faced with

9   Treatment Choices, respondents prioritised quality-of-life over life extension with

10 preference for TA and TC over TB which aligned with the strength of preference results for

11 these pairings; PTO results also indicated a substantial proportion of respondents made

12 limited trade-offs (extreme preferences). Examining agreement with the three societal

13 viewpoints indicated that our sample disagreed regarding the role cost should play in

14 decision-making. While 49% of respondents were assigned to Viewpoint 2, an account that

15 suggests that costs should not play a role in decision making, 46% of respondents

16 (Viewpoint 1 and 3) recognized the importance of achieving value for money.

17

18 Exploration of the relationship between different Decision Rules and Treatment Choices

19 found encouraging results as we observe broad consistency between respondents'

20 preferences elicited from those choices. An unexpected observation was the proportion of

21 respondents who selected Decision Rules that gave EoL treatments special consideration

22 and preferred the Non-EoL-QoL health maximizing treatment (TA) (33% of those selecting

23 DB and 44% of those selecting DC). This could be explained by the health gains of TA arising

24 over patients' lifetimes and so respondents might reasonably have interpreted these as far

exceeding the health gains likely to arise from 100 patients receiving either TB or TC. While this could indicate a disconnect between different types of preference, it could also be the case that preference for EoL is outweighed if the health gain from the alternative treatment is substantial. Unfortunately the online nature of our survey meant these issues could not be explored qualitatively.

Examining the pattern of response between respondents' viewpoints and their choices indicates that while in the majority of cases there is a pattern in line with expectations; it is not always the case. However, a priori hypotheses are not straightforward because viewpoints are wider and take in other issues, and choices were designed to examine support for NICE EoL policy rather than to mirror viewpoints exactly. Despite this limitation, interesting findings emerged. Results suggest that when respondents make choices they are more attuned to the limits of the NHS budget than when responding in more general terms when opportunity cost is not always explicit (Viewpoint Questions). More research is needed to examine the nature of consistency between principles, policies and choices, if policy is to be designed in areas of societal disagreement. As well as future work qualitatively exploring inconsistencies, the separation of preferences into different 'levels' – principles, policies and choices – of specificity and abstraction would enable examination of why and how respondents (dis)agree and whether there is potential for agreement in more-specific cases in the face of disagreement at the level of theory or principle (Sunstein, 1995).

The empirical literature eliciting societal values with respect to provision of EoL treatments has, to date, produced very mixed results with a similar number of papers reporting an EoL premium or no evidence of such a premium (Shah, 2017). Our survey methods, grounded in

a previous, in-depth study of the nature of perspectives (McHugh et al., 2015), suggest a substantial proportion of the population (roughly a third of our sample) has broadly utilitarian motivations, preferring policies promoting cost effectiveness and maximizing health gains. In contrast to current NICE policy, which favours *life-extending* treatments at the EoL, our results also suggest that policies and treatments that prioritise quality-of-life are more important to the general population than those that prioritise length of life. On the basis of these findings, and the findings of Pinto Prades et al. (2014) and Shah et al. (2014), life extension appears to be less valued by the public than quality-of-life at the EoL. This is an important observation given that media reports and other policy initiatives (e.g. Cancer Drugs Fund) might suggest that society values life-extending treatments above other treatments and services competing for funds. If additional societal benefits are not generated from prioritising funding for life-extending treatments at the EoL, then cost-effective treatments for non-EoL patients may be displaced by policies that prioritise less efficient treatments.

Limitations

There are a number of limitations to the study design and details of the survey that should be acknowledged. Firstly, respondents were quota-sampled to represent the general population with respect to standard socio-demographic variables, but they were members of YouGov's online survey panel, which introduces self-selection bias. Furthermore, a trade-off of undertaking large scale survey work is that we were unable to collect qualitative data alongside the main survey. As such, we could not explore qualitatively: why, in some cases, the relationships between Decision Rule and Treatment Choice responses, or between

policy choices and viewpoints, were not as expected; whether and to what extent respondents viewed TA (Non-EoL-QoL) as the health maximizing treatment; nor respondents' rationales for their treatment choices to move beyond the circularity of re-stating details of the scenarios chosen.

Secondly, question ordering may have affected responses. We took the view that there was need for a consistent ordering as Viewpoint Questions introduce different issues related to the topic, and Treatment Choice selection was considered to flow more naturally from the choice of a high-level Decision Rule, but we cannot rule out the ordering effects that may have followed from this design.

Thirdly, the Decision Rule question could have introduced a 'status quo' framing effect by *stating* that the NHS *currently* applies a 'value for money' test before agreeing to provide new medicines. Thus respondents might have seen this as a choice between the status quo (DA) and something new – DB or DC – although the status quo is in reality closer to DC (along with a preference for life extension). Respondents could have been unwilling to choose a policy that contradicts the current agenda. However, our results show that DC (with a quality-of-life preference) was the most popular choice.

Fourthly, as shown in Table 2, no viewpoints clearly correspond to a preference for DB or TB because none of the three viewpoints from our original study would clearly predict those decision rule or treatment choices (McHugh et al., 2015). DB was included to examine if respondents valued *all* new treatments for terminal illnesses and TB represents NICE's current EoL policy.

Fifthly, in the introduction to the Decision Rule question the terms 'drugs' and 'treatments' could be construed as being interchangeable; this was not our intention and a clearer differentiation should have been made between the two as per NICE technology appraisal guidance (NICE, 2017). Whilst this could have led to different interpretations amongst respondents, we were given no indication of this during the piloting phase and the decision rule and treatment choice scenarios all refer to 'treatments'. The focus on treatments is similar to the approach used in the EoL preference elicitation literature summarized in the 'Background' section. However, whether 'treatment' refers to drugs or something else is generally unstated in these papers; exploring preferences for different types of treatment at the EoL could be an interesting source of future research.

Lastly, respondents were assigned to a viewpoint based on their highest aggregate score on associated statements. While this gives an indication of what viewpoint respondents are most like it does not account for respondents being closely associated with multiple viewpoints. Given that quality-of-life receives substantial support from the policy choice questions, this could help to explain the unexpectedly small proportion of respondents (9%) assigned to Viewpoint 3.

Conclusion

This study challenges NICE's current EoL guidance and contributes, through use of innovative methods, to the growing body of empirical evidence around this topic. Elicited preferences indicate that for policy to better reflect societal values consideration needs to

1 be given to quality-of-life improving treatments at the EoL and to the cost of new

2 treatments. Our findings also caution against simplistic approaches to summarizing societal

3 values using measures of central tendency. The methods used reveal plural societal views

4 and that different relationships can exist between societal viewpoints and preferences

5 expressed at different levels of specification. Future research should combine qualitative

6 and quantitative methods to better understand the nature and distribution of societal

7 values across different levels of specificity and abstraction. There would appear to be great

8 potential in developing empirical studies of societal values that combine health economic

9 and ethics based approaches, examining the relationship between principles/ arguments

10 and choices/ preferences.

11

Appendices

13 Appendices can be found at: *[end of paper].*

14

Conflicts of Interest

16 None.

17

Acknowledgements

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21

Appendix 1 Script for Introductory Animation

see   http://www.gcu.ac.uk/endoflife/onlinesurvey/introductoryanimation/   for introductory animation

1. The National Health Service is funded directly by the public.

2. The NHS spends its budget on many things, including doctors, nurses, beds, new drugs and treatments.

3. Although the health service budget is very big, it is still a fixed amount. There is never enough money to do everything we want.

4. Of course, the NHS budget could grow in the future.

5. But this research is about the money the health service has now, and the best way to spend it.

6. Because the budget is fixed, difficult decisions have to be made about how to spend NHS money.

7. When the NHS provides a service, the public benefits. But the public will not benefit if that service is not funded.

8. Because of this, and because the public pays for the NHS through its taxes, it is important that decisions on how to spend NHS money take into account the views of the public.

9. For example, thinking generally about all NHS patients, should we concentrate our funding on the treatment of people who are most severely ill? Or perhaps we should focus our spending on treatments that give people a better quality of life? Or should we prioritise the funding of treatments that help people to live longer?

10. In this research project, our focus is on NHS treatments that help terminally ill patients live longer.

11. These treatments will not cure the person's illness, but will extend their life, usually by weeks or by months.

12. Whatever money is spent on these treatments is not then available to spend elsewhere in the NHS.

13. Because of this, the cost of treatments for terminally ill people, and how much good they do, has to be considered in relation to all other NHS spending.

14. These are difficult decisions to make, and there are no right or wrong answers.

15. As a member of the public, we need to know your views on this important topic.

1   **Appendix 2 Decision Rule Question**

2

3   ***italics highlight programming notes***

4

5   As there is a limit to the health budget, the NHS applies a 'value for money test' before
6   agreeing to provide new medicines. This test looks at the extra costs and the health benefits
7   of new medicines compared with the best treatments already provided by the NHS, for that
8   condition.

9   The value for money test makes sure the NHS does not spend money on high cost
10   treatments, which provide only limited health benefits, but funds those treatments that
11   deliver better value for money.

12   There are some drugs, for terminally ill patients, which do not pass this value for money
13   test, because they do not cure patients. These medicines might extend life or improve
14   quality of life for patients for a short period of time, but often at quite high cost.

15   The NHS is considering different ways of assessing drugs like these. We want to know what
16   you think of a number of different policies.

17   It is important to keep in mind that if money is spent on these medicines for people with
18   terminal illnesses, it is not available to spend on other treatments in the NHS.

19   **Q1**. Which one of the following policies do you **agree with most**? Please click the box below
20   the policy you agree with.

POLICY A	**POLICY B**	**POLICY C**
All new treatments, including those for terminal illnesses ***must*** pass the same value for money test. Only those treatments that pass the test are provided from the NHS budget.	***All*** new treatments for terminal illnesses should be given special consideration (a different value for money test should be applied for new treatments for terminal illnesses).	It depends.. ***some*** new treatments for terminal illnesses should be given special consideration (a different value for money test should be applied for new treatments for terminal illnesses).
☐	☐	☐

21
22
23   *If respondent ticked box:*
24   ***A*** *– finish.*
25   ***B*** *– go to Q2.*
26   ***C*** *– go to Q4.*
27
28
29

34

Q2. In response to Q1 you selected Policy B.

You said that *all* new treatments for terminal illnesses should be given special consideration (a different value for money test should be applied for new treatments for terminal illnesses).

Which of the following do you **agree with most** (please tick only one box)?

☐ all new treatments for terminal illnesses should be given special consideration, regardless of their cost

☐ all new treatments for terminal illnesses should be given special consideration, but there should be a limit to the amount the NHS will pay

Q3. In response to Q1 you selected Policy B.

You said that *all* new treatments for terminal illnesses should be given special consideration (a different value for money test should be applied for new treatments for terminal illnesses).

Health benefits can either extend life or improve the quality of life. Which of the following do you **agree with most** (please tick only one box)?

☐ Treatments for terminal illnesses that increase the length of a patient's life are more important than those that improve a patient's quality of life.

☐ Treatments for terminal illnesses that improve a patient's quality of life are more important than those that increase the length of a patient's life.

☐ Treatments for terminal illnesses that increase the length of a patient's life or that improve quality of life are both equally important

☐ Life extending treatments are more important, but they should only be provided if a patient's quality of life is good

1   **Q4.** In response to Q1 you selected Policy C.
2
3   You said it depends.. *some* new treatments for terminal illnesses should be given special
4   consideration (a different value for money test should be applied for new treatments for
5   terminal illnesses).
6
7   Which policy do you **agree with most**? You can tick only one box.
8

POLICY C1	POLICY C2	POLICY C3
New treatments that extend life for terminally ill patients should be given special consideration.	New treatments that improve quality of life for terminally ill patients should be given special consideration.	New treatments for terminally ill patients should only be given special consideration *depending on* (something else) *Please go to Q5*
☐	☐	☐

9
10   *Only respondents who selected Policy C3 answer Q5. Respondents selecting Policy C1 or C2*
11   *move on to Q6.*

36

1 **Q5.** In response to Q4 you selected Policy C3. You said treatments for terminally ill patients
2 should only be given special consideration *depending on (something else). . . .*
3
4 Which policy do you **agree with most**? You can tick only one box.
5

POLICY C3a	POLICY C3b	POLICY C3c	POLICY C3d
Treatments that extend life for terminally ill patients should be given special consideration (but not if their quality of life will be poor).	Treatments for patients who have only known that they were terminally ill for a short time should be given special consideration.	Treatments for terminally ill patients who have not had their fair innings - in terms of the length of their life should be given special consideration.	Treatments for terminally ill patients should be given special consideration *if* . . . . . *Please type in your own answer in the space below*
☐	☐	☐	☐

6
7 You selected Policy C3d in Q5, please insert your reason for this selection below.
8
9 **"**Treatments for terminally ill patients should be given special consideration if . . . . .
10 _____
11 _____
12
13
14 **Q6.** In response to Q4/5 you selected Policy *'insert corresponding policy letter from either*
15 *Q4 or Q5'.*

16 You said (*insert policy letter and description from Q4/5)*
17
18 Which of the following do you **agree with most**, please tick only one box.
19
20 ☐ Policy *'insert corresponding policy letter from either Q4 or Q5'* should be given
21 special consideration, regardless of their cost
22
23 ☐ Policy *'insert corresponding policy letter from either Q4 or Q5'* should be given
24 special consideration, but there should be a limit to the amount the NHS will pay.
25
26
27
28
29
30

Notes

In the programmed question respondents could mouse-over the following terms for definitions:

Value for money test: "The value for money test compares the extra costs and benefits of new medicines compared to existing treatments and makes sure the NHS does not spend money on high cost treatments that provide only limited health benefits."

Pass the test: "There are some drugs for terminally ill patients near the end of their life which do not pass this value for money test, because they do not cure patients and so health benefits are quite limited, often at high cost."

NHS budget: "If NHS money is spent on these medicines for people with terminal illnesses, it is not available to spend on other treatments in the NHS."

Special consideration: "Special consideration means that treatments for people with terminal illnesses are provided even if they do not pass the value for money test that all other treatments must pass. There may still be limits, but those limits would be higher than for other treatments".

Terminal illness: "Terminal illnesses cannot be cured and will lead to patients' death, usually within a year."

1   **Appendix 3 Treatment Choice Question**
2
3   ***italics highlight programming notes***
4
5   The NHS has a fixed, additional budget available to spend on treatments for people in your
6   area and is considering which of **three new treatments** to provide from this money. **Only**
7   **one treatment can be provided**.
8
9   Below are descriptions of the three treatments. Which treatment should be provided?
10

TREATMENT A

Patients are currently suffering from a
<u>non-life threatening illness</u> that causes
them discomfort and fatigue. The illness
also reduces their mobility and ability to
undertake their usual activities. This
occurs a <u>few times throughout every year</u>
<u>for the rest of their life</u>. Each episode
lasts for up to 2 weeks.

A new treatment is available that will
reduce their symptoms and make
patients feel better, improving their
<u>quality of life for the rest of their life</u>.

Funding will mean that <u>100 patients</u> can
be treated in the next year.

TREATMENT B

Patients are currently suffering from a
<u>terminal illness</u> that causes them
discomfort and fatigue. The illness also
reduces their mobility and ability to
undertake their usual activities.

A new treatment is available for
terminally ill patients in the <u>last year of</u>
<u>their life</u>. The treatment will <u>extend</u>
<u>patients' lives by three months</u>. It will not
improve their quality of life.

Funding will mean that <u>100 patients</u> can
be treated in the next year.

TREATMENT C

Patients are currently suffering from a
<u>terminal illness</u> that causes them
discomfort and fatigue. The illness also
reduces their mobility and ability to
undertake their usual activities.

A new treatment is available for
terminally ill patients in the <u>last year of</u>
<u>their life</u>. The treatment will reduce their
symptoms and make patients feel better,
improving their <u>quality of life</u>. It will not
extend their life.

Funding will mean that <u>100 patients</u> can
be treated in the next year.

Q1. Which treatment should be provided? Click on the 'Treatment' you think should be provided.

Now from the remaining two treatments click on the 'Treatment' you think should be provided.

If only one treatment could be funded, you said that Treatment (*insert most preferred*) should be provided.

Treatment (*insert second most preferred*) was your next most preferred after treatment (*insert most preferred*).

Is that correct?

Yes/ No – (*if No go back and choose again*)

Q2.

Show description of their 'preferred treatment from Q1'

What was the most important reason for selecting [Treatment *insert treatment letter A-C]* for funding? Tick only one box.

a. End of life treatments are very important ☐

b. The treatment will extend life ☐

c. The treatment will improve quality of life ☐

d. The illness affects patients for the rest of their life ☐

e. I preferred supporting the non-life threatening illness ☐

f. The patients with terminal illnesses will die anyway ☐

g. This treatment will provide a larger health benefit gain ☐

h. Other , please specify ☐

_____ *space to specify 'other'* _____

1   Q3a. Your 'preferred treatment' from Q1 was Treatment *'insert letter of preferred*
2   *treatment'* and your **'**second-best treatment' was Treatment *'insert letter of second-*
3   *best treatment'*. <u>Only one treatment can be funded.</u>

4

5   Suppose the cost of your 'preferred treatment', Treatment *'insert letter of preferred*
6   *treatment'*, has now changed, and fewer patients can be treated as a result.

7

8   While your 'second-best treatment', Treatment *'insert letter of second-best treatment'*, will
9   still treat 100 patients, (if funded), the number of patients that your 'preferred treatment',
10   Treatment *'insert letter of preferred treatment'*, is now less.

11

12   When 100 patients could be funded by each treatment, you chose to fund Treatment *'insert*
13   *letter of preferred treatment.*

14

15   Your choice is shown by the black circle below.

16

Choice [check box]	Insert Short Description of 'preferred treatment'	Insert Short Description of 'second – best treatment'	Choice [check box]
⬤	100 patients	100 patients	

17

18

19   What if only 10 patients could be treated with Treatment *'insert letter of preferred*
20   *treatment'?* Would you prefer to fund 10 patients with Treatment *'insert letter of preferred*
21   *treatment'* or would you prefer to fund 100 patients with Treatment 'insert *letter of second-*
22   *best treatment'?* Please indicate your preference by clicking on the [check box] below.

23

Choice [check box]	Insert Short Description of 'preferred treatment'	Insert Short Description of 'second – best treatment'	Choice [check box]
	10 patients	100 patients	⬤

24

25   *[In this example, respondent chose 'second-best treatment' – shown as the black circle.*
26   *Following response to the above questions, a full table appears with the second row and last*
27   *row completed based on the above two responses, all other numbers in the table should*
28   *appear but be greyed out.]*

29

30   What if we could only fund 90 patients with Treatment *'insert letter of preferred*
31   *treatment'?* Would you prefer to fund 90 patients with Treatment *'insert letter of preferred*
32   *treatment'* or would prefer to fund 100 patients with Treatment 'insert *letter of second-best*
33   *treatment'?* Please indicate your preference by clicking on the corresponding [check box]
34   below.

35

Choice [check box]	Insert Short Description of 'preferred treatment'	Insert Short Description of 'second – best treatment'	Choice [check box]
⬤	100 patients	100 patients	
⬤	*90*	*100*	
⬤	*80*	*100*	
⬤	*70*	*100*	

	60	*100*	●
	50	*100*	●
	40	*100*	●
	30	*100*	●
	20	*100*	●
	10	*100*	●

[This question repeats replacing the number for the 'preferred treatment' option with numbers from the second column alternating between, 20, 80, 30, 70, 40, 60, 50]

From the table above you would prefer Treatment (*insert letter of second-best treatment*) when (*insert number of patients when the black circle moves to the right hand column – 60 in the above example*) patients would be funded by Treatment (*insert letter of second-best treatment*).

Now, suppose there were *(insert x)* patients that could be funded by *(insert preferred treatment)* and 100 patients who could be funded by *(insert second best treatment)* which would you choose to fund?
(note – x is the midpoint between: the lowest choice on the left hand column and the highest choice in the right hand column)

Choice [check box]	*Insert Short Description of 'preferred treatment'*	*Insert Short Description of 'second – best treatment'*	Choice [check box]
	[x] patients	100 patients	

Q3b *[only for respondents whose choice is their 'preferred treatment' option at 10]*

You said that you would prefer that 10 patients are funded by Treatment *'insert letter of preferred treatment'* compared to funding 100 patients with Treatment 'insert *letter of second-best treatment'*.

Now, suppose there was only 1 patient that could be funded by *(insert preferred treatment)* and 100 patients who could be funded by *(insert second best treatment)* which would you choose to fund?

Choice [check box]	*Insert Short Description of 'preferred treatment'*	*Insert Short Description of 'second – best treatment'*	Choice [check box]
	1 patient	100 patients	

[if choice = preferred treatment then end; if second preferred then present again but with 5 patients on left and 100 on right]

REPEAT FOR COMPARISON BETWEEN MOST PREFERRED AND LEAST PREFERRED.

1   **Appendix 4 Viewpoint Questions: statements selected for survey (by viewpoint)**

2

Statement Number (from initial Q study)	Viewpoint 1
3	Treatments should be directed towards people who have a greater chance of survival.
5.	At the end of their life, patients should be cared for at home with a better quality of life rather than have aggressive and expensive treatments that will only extend life for a short period of time.
26.	It is wrong to raise hopes and expectations by making a special case for treatments that will only extend life by a short time.
38.	The health system should be about getting the greatest benefit overall for the population.
2.	We should support an individual patient's choice for treatments that give short life extensions.
13.	I would place more value on end-of-life treatments than many medical treatments for non-terminal conditions.

	Viewpoint 2
17.	If a life-extending treatment for terminally ill patients is expensive, but the only treatment available, it should still be provided.
20.	We all have the right to life.
27.	To extend life in a way that is beneficial to the patient is morally the right thing to do.
37.	All human life is precious.
1.	It is not worthwhile devoting more and more NHS money to someone who is going to die soon anyway.
33.	End-of-life drugs are not a cure, they are life-prolonging. There is no point in delaying the inevitable for a short time.

	Viewpoint 3
25.	We should spend proportionately more on patients when we feel those patients have not had their fair innings - in terms of the length of their life or the quality of that life.
31.	Treatments that are very costly in relation to their health benefits should be withheld.
34.	Patients at the end of life will grasp any slightest hope but that is not a good reason for the NHS to provide costly treatments that may extend life by a short time.
41.	I wouldn't want my life to be extended just for the sake of it - just keeping breathing is not life.
23.	A year of life is of equal value for everyone.
24.	You can't put a price on life.

3   ***Grey shaded statements are negatively associated with the viewpoint.***

1 **Appendix 5 An example of the two methods used to aggregate PTO responses**

2

3 Calculation of the 'ratio of means' involves assigning a value of 1 to the most-favoured
4 treatment in each individual choice, with the less-favoured treatment receiving a value
5 equal to the number of patients in the most-favoured group divided by the number of
6 patients in the less-favoured group. Means across all respondents for each treatment (X and
7 Y) are then calculated and then ratio of means determined. 'Median of ratios' comprises
8 calculating ratios, X/Y (alternatively Y/X could be utilised), for each individual respondent
9 and then taking the median of ratios across all respondents. These calculations are adapted
10 from Pinto-Prades et al. (2014).

Respondent ID	Raw responses*		Ratio of Means (RoM)		Median of ratios	
	X	Y			X based	Y based
1	25	100	1.00	0.25	0.25	4.00
2	10	100	1.00	0.10	0.10	10.00
3	5	100	1.00	0.05	0.05	20.00
4	100	5	0.05	1.00	20.00	0.05
5	100	10	0.10	1.00	10.00	0.10
			Mean=0.63	Mean=0.48		
			RoM (X/Y)	**1.31**	**0.25**	**4.00**
			RoM (Y/X)	**0.76**		

11 (*) Number (Ni) of patients X(Y) which are considered equivalent to 100 patients Y(X).

12

13

14

15